

AIDS Brief

for professionals

Health Care Workers



HIV/AIDS is among the top ten 'killers' worldwide. Given the current levels of HIV infection, it may soon move into the top five (UNAIDS/WHO Report, 1998). By the end of the 20th century, 33.6 million men, women and children had been infected with HIV. AIDS is clearly one of the greatest public health challenges of the era and, whilst there are continuous calls for a multisectoral response to the epidemic, there is abundant evidence that that response must, in most instances, be led by dedicated, committed health care workers. This AIDS Brief describes how the AIDS epidemic is redefining the context of care and the challenges which it is presenting to health care workers.

Definition: A health care worker (HCW) is defined as any person whose activities involve contact with patients in a health care setting. This includes employees, students and contractors; professionals such as doctors, nurses, midwives, attending clinicians, researchers and public safety workers; and lay workers such as trained volunteers, community health and TB workers, counsellors and traditional healers. For the purposes of this AIDS Brief however, the emphasis is on professional HCWs.



BACKGROUND

In every country people living with HIV/AIDS have to navigate a confusing and often contradictory health and social service bureaucracy. At the same time they have to face the stigma and profound discrimination associated with HIV and AIDS. Estrangement of family and friends is common and support is often lacking. Negative attitudes, rigid beliefs and values, and misinformation can significantly affect the HCWs' ability to provide effective, respectful and dignified care for PWAs and their families. Compounding this is the fact that HCWs themselves may find talking and working with issues related to sexuality, death, drug use, prejudices, morals and religious beliefs difficult.

Discussion of some subjects may be taboo and associated with feelings of embarrassment, shame and guilt. And finally, at the beginning of the 21st century, there are very few HCWs who have not been affected by family members and friends dying from HIV/AIDS whilst, at an even more personal level, there are many HCWs who are themselves living with HIV/AIDS.

How then can the HCW interface with his or her patient? Working in the AIDS field, particularly in the area of care, requires of HCWs a unique introspection to:

- assess how comfortable they are with illness, death and grief;
- examine their capacity to express compassion, regardless of how they may feel about the conduct that led to infection;
- examine their willingness to be exposed to settings and lifestyles that are unfamiliar;
- examine how they feel about end-of-life options;
- realise that acceptance by those they serve may take time;
- realise that many may oppose their work;
- assess their need for additional training;
- assess how long they can be involved;
- anticipate needing a support system of their own; and
- realise that their experiences will change their lives.

Noerine Kaleeba, the founder of TASO (The AIDS Support Organisation in Uganda) lost her husband to AIDS. She had this to say in her book *We Miss You All - AIDS in the Family*:

“I began to notice that some of my colleagues were finding it hard to deal with me. I had not been prepared for these reactions from my own people. I would walk into the staff room and people would suddenly stop chatting, suddenly it was time for everyone to get back to work on the wards. I knew that I was not included in conversations, or people would talk to me in very, very excessively kind tones. I was surprised by this kind of behaviour from fellow health professionals ... If they were unable to deal with me as an ordinary human being, how were they relating to their AIDS patients?”

Society entrusts health care professionals and indeed all health care workers with the responsibility for preventing and controlling disease and caring for those who are infected or ill. Most HCW professional associations have developed codes or guidelines to assist their members in how to approach the complex area of HIV/AIDS care, the ethics

which should guide decision-making, and the roles and responsibilities which should be assumed. For example, as early as 1987, the Global Programme on AIDS (GPA) and the International Council of Nurses (ICN) issued a Joint Declaration on AIDS which set out the rights and responsibilities of nurses throughout the world in preventing the transmission of

HIV and in caring for people infected with HIV. The Director of GPA summarised the situation at that time by saying that nurses have ‘a professional responsibility to remain clinically up-to-date and positioned to offer confident, competent, compassionate and relevant care to the escalating numbers of people living and dying with HIV-related illnesses’.

KEY PERFORMANCE AREAS

Key performance areas for HCWs working in the field of HIV/AIDS identify the *client* not just as the patient, but as the patient, the family and the community. The *context* within which the HCW interfaces with clients may be the home (for psychological support, home care and palliative or terminal care), hospice (for palliative or terminal care), the clinic (for ambulatory care), the hospital (for diagnostic or in-patient care) and the community (for advocacy, education and disease prevention).

Continuum of care

Combining counselling, education, support and care services is necessary to provide a holistic continuum of prevention and care. HCWs are involved at all points along the continuum of care - from hospital to home and vice versa and involving clinical management, direct patient care, education, prevention, counselling, palliative care and social support.

Perhaps one of the most difficult problems that HCWs must deal with is that of scarce resources – a problem common to both poor and wealthy nations. HCWs are constantly faced with the need to make decisions about treatment for patients with AIDS which, whilst aiming to alleviate suffering and minimise morbidity, must be realistic and affordable within the financial

and technical constraints of the health system within which they operate.

Ethics

General ethical issues which guide all health care include a duty to provide care and a responsibility to protect patients. These apply to HIV/AIDS as well, as do the principles of professional secrecy and patient confidentiality. HCWs are no different from the general population in their feelings of fear, stigma and discrimination related to HIV/AIDS. Training on ethics and human rights, and their application to HIV/AIDS, should be an integral component of all basic, in-service and post-basic training for HCWs.

Voluntary counselling and testing (VCT)

VCT can be provided in a range of settings, including government outpatient and STD clinics, maternal and child health clinics, specialised VCT centres, HIV/AIDS care and support organisations, and through outreach or mobile services. Good counselling assists people to make informed decisions, cope better, lead more positive lives and prevent HIV transmission. Knowledge of HIV status can reinforce safer sexual practices, inform decisions about future pregnancies, allow access to a continuum of care in order to seek early medical treatment and be linked to other health and social services.

Knowledge of HIV status in the context of pregnancy allows for decisions to be made relating to possible termination of pregnancy, potential access to ARV treatments, modified midwifery and obstetrical practices and breastfeeding.

HCWs will need additional training in pre- and post-test HIV counselling. They may also need additional training to help them to deal non-judgmentally with clients in often difficult situations. And they will require a rigorous understanding of the importance of confidentiality.

Prevention and education

Primary prevention aims to prevent the acquisition of infection and disease (safer sexual behaviour and the use of condoms). Secondary prevention entails the promotion of health-seeking behaviour, the provision of clinical services and support and counselling services. Prevention and education programmes have to take place within a country's macro strategies (public health policy and laws) as well as at the micro or individual level. HCWs are increasingly required to act as HIV/AIDS educators. Traditionally however, HCWs have not been trained to discuss sensitive issues like sexuality and sexual practices and they may require training, including training in communication, in order to fulfil this role.

The HIV/AIDS education role of HCWs could encompass any or all of the following target groups - other health workers and social service personnel, family and friends, youth and school children, parent groups, sex workers, pregnant women, community members and civic leaders, refugees, traditional healers and volunteers. The topics they may be required to cover could include promoting the use of sterile injecting equipment by intravenous drug users, traditional healers, other HCWs; information for young people about how to avoid the risks of contracting HIV, preventing the transmission of HIV to others and the hazards of certain high risk behaviours, particularly unsafe sex practices. To assist in this, it should be noted that PWAs are often the best advocates and activists for social and behavioural change.

Continuing education for HCWs

HCWs have an obligation to be well informed about HIV: however research, practice and treatment for the prevention and care of HIV disease are changing so rapidly that they need to have on-going education to remain up-to-date in their knowledge, skills and practices. For this to happen there needs to be comprehensive HIV/AIDS education, in basic training as well as continued education, which is often, not a priority in health care settings.

Protection and infection control

HIV and other blood-borne infections can be transmitted in the health care setting from patient to HCW, from patient



to patient, from HCW to patient and from HCW to HCW.

The risk depends on practices, the prevalence of HIV in the local population and the amount and frequency of exposure. Whilst most patient care does not carry any risk of HIV transmission, in many situations, where there is risk, this is compounded by downsizing and staff reductions in the wake of health service restructuring, lack of basic protective equipment and cleaning materials and the alarming rise in the number of people with HIV/AIDS.

The occupational risk of becoming HIV infected following a needlestick injury from an HIV positive source is approximately 0.3%. Though small, preventing or minimising the risk of occupational exposure and the transmission of HIV should be a priority in all health care settings. Universal infection control procedures, in both emergency and non-emergency situations and at all times, regardless of whether or not a patient is known to be HIV infected, must be adopted. This encompasses risk assessment, risk reduction, setting standards and adopting safe techniques and procedures, proper planning and management of supplies as well as exposure management.

Care for the care givers

High levels of stress and burnout are experienced by HCWs working with patients with HIV/AIDS. This is related to their inability to save lives, the fact that many of their patients are young, that AIDS often affects whole families and the unpredictability of terminal AIDS care. Support groups and counselling, both

individual and group counselling, are helpful interventions in supporting HCWs working with patients with HIV/AIDS and their families.

Care for HIV infected HCWs

In the absence of any demonstrated risk, there is no ethical reason why an infected HCW should not perform any health procedure. However, a HCW who suspects they have been infected with HIV has an ethical responsibility to seek testing and counselling. Infected HCWs should receive appropriate medical care from a suitably qualified practitioner and should also obtain and follow expert advice on any necessary modifications to their practice that may be necessary to protect their patients.

Infected HCWs may require flexible working conditions, depending on their condition and job demands, to protect them from other infections (such as TB) and to continue their employment for as long as possible.

Epidemiology and research

It is essential that the collection of data on the prevalence and incidence of HIV be encouraged, as it is the only way to plan a public health response in a responsible manner. In addition to epidemiological studies, other research plays an important role in understanding the spread, control and treatment of HIV. It is important for HCWs who conduct or participate in any epidemiological or research studies to have a sound grounding in research ethics.



CHECKLIST

- What HIV/AIDS related modules are included in training programmes? Do these include ethics and human rights?
- How can a continuum of care be implemented? How can prevention and care be integrated across the continuum?
- How can PWAs, their families and primary care givers be directly involved in planning care?
- What treatments are cost-effective to prevent HIV related opportunistic infections and how should these be promoted, delivered and monitored?
- What are the minimum requirements which should be in place for ARVs to be made available to PWAs?
- What roles can the HCW assume in orphan care (direct physical care, advocacy, identification and registration, support)?
- How can relevant, accessible and acceptable VCT services be established and sustained?
- How can stress and burnout related to working in AIDS be managed?
- Do HCWs understand the basic philosophy of palliative care? Do they implement it; do they require training and resourcing to deliver palliative care?
- Are services youth and women friendly – recognising those who are particularly vulnerable to HIV infection?
- Is the health care setting safe in terms of occupational exposure to blood-borne pathogens? Is there education of HCWs about occupational risks, methods of prevention and procedures for reporting occupational exposures? Is protective equipment available and the means to clean up blood spills safely?
- Is there counselling for infected HCWs on care, occupational risks, continued practice, career change and job retraining opportunities?
- HCWs have a responsibility to become role models for other HCWs, organisations and communities. They should at all times behave in an ethical and scientifically responsible manner.
- Confidentiality must be respected and basic rights observed.
- Patients with HIV/AIDS have the same rights to appropriate treatment and care as any other patient.
- It is cost-effective to prevent many HIV-associated infections.
- Counselling is an integral part of the care of patients with HIV/AIDS and support networks are important.
- Testing for HIV should be done on a voluntary basis and with the informed consent of the patient. Informed consent should be obtained within the context of pre-test counselling. Test results should be given during post-test counselling to minimise the trauma of positive results.
- In all health care settings, the emphasis should at all times be on maintaining high standards of infection control regardless of whether or not a patient is known to be infected with HIV.
- Care can and should be integrated with prevention.

Guiding principles

As mentioned above there are many codes of conduct and sets of guidelines for individual health care professions. There is no single set of international norms; rather, some common guiding principles can be identified which should form the basis of any code or guidelines.

- HCWs have a moral and ethical responsibility to care for all people, including those with HIV/AIDS. HCWs and health institutions must not be discriminatory or judgmental.
- HCWs have a responsibility to advocate for compassionate, dignified and competent care for patients and HIV infected colleagues.

SUMMARY

Most people with HIV/AIDS are in the prime of life when they confront illness, disability, dependence, disfigurement and death. Few other diseases produce as many losses – loss of physical strength, mental acuity, ability to work, self-sufficiency, social roles, income and savings, housing

and the emotional support of loved ones. HCWs are the service providers who approach people with HIV/AIDS at the crisis points in their disease. Though stigma and the environment for care may create conditions that threaten the quality of care, all HCWs have a moral and ethical duty to

provide the best possible care for all people. In the era of HIV/AIDS, this requires that HCWs step out of their traditional roles and assume new responsibilities, not only in respect of their patients and colleagues, but also in respect of affected families and communities.

REFERENCES

- UNAIDS: *Fact sheets on HIV/AIDS: a desktop reference* (Draft) (1999)
- ICN: *Reducing the impact of HIV/AIDS on nursing/midwifery personnel: guidelines for National Nurses' Associations and others* (1996)
- Gilks, C et al: *Care and support for people with HIV/AIDS in resource-poor settings* (1998)
- WHO: *HIV prevention and care: teaching modules for nurses and midwives* (1993)
- CDC: *MMWR - Public health service guidelines for the management of health care worker exposures to HIV and recommendations for post-exposure prophylaxis* (1998)
- Nicholl, A et al: *Sexual Health and Health Care:*

- HIV/AIDS and STIs, global epidemiology, impact and prevention, ODA Health and Population Occasional Paper* (1996)
- UNAIDS publications: *HIV-related opportunistic diseases, technical update* (1998); *Prevention of HIV transmission from mother to child, strategic options* (1999); *Counselling and voluntary HIV testing for pregnant women in high HIV prevalence countries, elements and issues* (1999); *HIV in pregnancy: a review* (1999); *Sexually transmitted diseases: policies and principles for prevention and care* (1997)

Useful contacts

ICN (International Council of Nurses); 3 place Jean-Marteau CH-1201, Geneva, Switzerland,

Tel: 41 22 908 0100, Fax: 41 22 908 0101
WMA (The World Medical Association); Tel: 33 450 407575, Fax: 33 450 405937, E-mail: wma@iprolink.fr
IAPAC (International Association of Physicians in AIDS Care); 33 North LaSalle Street, Suite 2600, Chicago, Illinois 60602-2601, USA, Tel: 312 795 4930, Fax: 312 795 4938
e-mail: iapac@iapac.org, Website: <http://www.iapac.org>
AMA (Australian Medical Association) website: www.ama.com.au
AEGIS (AIDS Education Global Information System); Website: www.aegis.com
HEARD website: <http://www.und.ac.za/und/heard>

Prepared by: Rose Smart, HIV/AIDS Consultant, South Africa

Commissioning Editor: Professor Alan Whiteside, Health Economics and HIV/AIDS Research Division, University of Natal, Durban, South Africa

Series Editor: Rose Smart

Layout: TheWriteStuff, Durban

The individual authors of the AIDS Briefs series are wholly responsible in their private capacity for content and interpretation.

Funded by the USAID
Bureau for Africa,
Office of Sustainable
Development
Award No.
AOT-G-00-97-00375-00

